SLOGANS and EUPHEMISMS

The Functions of Semantics in Mental Health and Mental Retardation Care

Slogans and Euphemisms:

The Functions of Semantics In Mental Health and Mental Retardation Care

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An address commissioned by the Texas Department of Mental Health and Mental Retardation and supported by the Hogg Foundation for Mental Health

October 22, 1984
Austin, Texas

Hogg Foundation for Mental Health
The University of Texas
Austin, Texas 78713
1985

TABLE OF CONTENTS

FOREWORD

It is a privilege for me to introduce to you this afternoon as our special lecturer a person for whom I have a great deal of respect and admiration. She is a person who has made outstanding contributions to our field. As you will see, she also has some remarkable personal qualities: she truly cares about patients and clients as well as those who serve them and those who advocate and volunteer on their behalf.

With respect to her professional credentials, I could say about her that she has a Ph.D. in Sociology from the University of Connecticut, that she is a Professor of Psychiatry at the University of Maryland, and that she has accumulated in her professional career to date one of the most impressive catalogs of accomplishments to be found anywhere, and I will touch on just a few highlights of those accomplishments momentarily.

But that sort of listing does not really tell you about our speaker, Dr. Leona Bachrach.

To indicate to you something of the importance of her work, let me cite some of the subject areas—and this is not a complete list—in which Dr. Bachrach is a recognized authority:

- the chronically mentally ill
- deinstitutionalization
- the homeless mentally ill
- the young adult chronic patient
- evaluation of mental health programs
- continuity of care
- model programs
- the concept of least restrictive alternative
- general hospital psychiatry
- the reemergence of the concept of asylum for mental patients

I submit that it would not be possible today to have a serious or scholarly discussion about any of these vital issues without prominent mention of Dr. Bachrach's seminal publications in these fields.

She is a teacher, lecturer, and writer of international stature. She has brought her extensvie background and knowledge to bear on the challenges and problems that we—as providers, advocates and consumers—face on a

daily basis, and, I might add, will continue to face throughout the eighties and beyond.

Dr. Bachrach's ability to organize, to conceptualize, to identify the salient features of and outline solutions to these problems and challenges, and to share her insights with us via her eloquent prose has led to her being one of the most widely cited and quoted authors in the mental health field.

I would add that Dr. Bachrach speaks her mind. There are no sacred cows for her. She has not hesitated to challenge some of the beliefs and assumptions that are widely held in the mental health field—when she feels such challenges are appropriate.

Some of the most penetrating of her critical analyses have concerned use and misuse of language—popular buzzwords and use of vague and imprecise language—in short, the use of slogans and euphemisms in the mental health field. Thus, the focus of this afternoon's talk, where she will bring together her observations of and insights into this significant but seldom recognized or discussed aspect of MHMR care.

Before turning her over to you, I want to mention just a few of the things she has done. As I said, she holds a Ph.D. in Sociology from the University of Connecticut. Currently, she is Research Professor of Psychiatry at the Maryland Psychiatric Research Center, a part of the University of Maryland School of Medicine, and Senior Consultant to the Maryland state mental health agency in the area of deinstitutionalization.

In 1977 she joined the staff of the President's Commission on Mental Health and contributed significantly to two of the most important task panel reports which appeared in Volume II of the *Report of the President's Commission on Mental Health.*

Finally, in December 1982, Dr. Bachrach was elected to Honorary Fellowship in the American Psychiatric Association—a distinction awarded to a very small group of non-psychiatrists—which gives you some indication of the esteem in which she is held in the mental health field.

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INTRODUCTION

The semantics of service delivery is a subject that's very close to my heart. For a number of years now I've been wrestling with thoughts about how words relate to the policy of deinstitutionalization—and how the policy of deinstitutionalization relates to words (Bachrach 1980a, 1980b, 1981, 1982, 1983a, 1984a, 1984b). This topic is endlessly fascinating to me. I sometimes despair of it—but I never tire of it. And today I want to share some of my thoughts with you.

But, of course, I don't think about deinstitutionalization *all* the time. Sometimes, in fact, when I have some free time, I like to read literary criticism. I have the fantasy that this gets me away from the things I usually deal with—like thinking about services for people who are severely disabled and all the frustration and sometimes despair that are implied in the pursuit.

Then I find out that the two worlds—the one of literary criticism and the other of service planning—aren't really all that far apart, after all. A. Bartlett Giamatti (1984), the President of Yale University, has written a very well-received analysis of Renaissance literature. He contends that Renaissance man had a deep respect for the "power of language." To the Renaissance man, says Giamatti, "words were units of energy," and, through their use, "man could assume forms and aspire to shapes and states otherwise beyond his reach."

When you get right down to it, what Giamatti says about Renaissance men of letters is not all that far removed from what you run into when you think about the needs of—and try to plan services for—people who have severe and persistent mental disabilities. Here, too, words are immensely powerful devices. They determine the questions that we ask—and the questions that we fail to ask—in service planning and service evaluation. In this way, they very much control the dimensions of our service system.

My presentation today is going to be all about some semantic habits that we've developed in our field. We use words to mollify, evade, inflame, and incite—and often we're not even aware of what we're doing. No only do we use words that lack consensus; we sometimes also use words indiscriminately. And these are the kinds of things I want to talk about.

In view of all this, I think that it's only fair for me to try to share with you at the outset one of my own verbal biases. And I'll start by confessing to you that—maybe as the result of my own history of physical illness—I experience some uneasiness when the word "client" is substituted for the word "patient." John Talbott (1984), the current President of the American Psychiatric Association, has a similar reaction. Talbott writes about this in a recent issue of the *Psychiatric News*. He explains that to be a patient is also to gain access to certain benefits that aren't available to people who are regarded as clients. We can think of these benefits, if we want to, as entitlements—although I think that the term entitlement itself has distinct monetary connotations (Ehrenreich 1982), and I'm referring now to concerns that are really more qualitative in nature.

Speaking from the perspective of the dedicated physician that he is, John Talbott takes a position that is reminiscent of an eloquent statement by the late Franz Ingelfinger (1980), who perceived, and wrote about, the world as both a terminally ill patient and a renowned physician. Ingelfinger wrote that people who are sick already have enough to deal with, without having to expend energy on seeking their own boundaries—and that the patient designation has implicit in it a certain amount of comfort. Only when he accepted his own patient identity, wrote Ingelfinger, was he able to mobilize his strengths and resume such ordinary life activities as teaching, lecturing, and writing.

At the same time, I can readily understand why some people who work with the mentally retarded would prefer not to use the word patient. So I'll compromise and use both words, patient and client, today. I'll use the word patient to refer to people who are mentally ill and the word client to refer to people who are mentally retarded. And when I talk about both of these groups together, I'll refer to them as mentally disabled people.

Furthermore, I'll be limiting my remarks today to those among the mentally disabled who are chronically so. Now, I know that the word "chronic" has pejorative connotations for some people, too (Word "Chronic" 1981). But all I mean by it is that I'm going to be centering my remarks on people who have severe and persistent mental disorders that render them dependent on mental health or mental retardation services for a very long time—often for life (Goldman et al. 1981; Peele & Palmer 1980).

Just one more kind of introductory comment: Throughout my comments this afternoon I'm going to be focusing on some key concepts and words—

words that are familiar to all of us who are involved with services for the mentally disabled today, words like "asylum" and "least restrictive alternative" and "young adult chronic patient." And I'll necessarily be saying quite a lot about something that's called "deinstitutionalization."

At the end of this presentation I'll try to put my remarks in perspective by suggesting some reasons that semantics operates as it does in our field. And I'll talk about the need to clear up our concepts and our thinking if we're going to profit from past errors in service planning.

I'd like to begin my discussion this afternoon by making a statement and then asking how many of you in the audience agree or disagree with it.

This is the statement:

The goal of deinstitutionalization is to provide, for mentally disabled people who do not require institutionalization, humane and sensitive care in the least restrictive community alternative.

Does anybody here seriously disagree with this statement? If anybody does, let's try to go into the matter later, during the discussion period. But I doubt that many people here this afternoon would take serious issue with that statement—because I think that it's a faithful and accurate description of what deinstitutionalization is *supposed* to do.

But I need to point out something to you. That statement contains at least three terms that are very imprecise—"deinstitutionalization," "community," and "least restrictive alternative." Each of these terms means different things to different people. Yet, we in this room can agree with a "principle" that's implied in that statement—even though the principle is expressed in words that aren't at all clear.

There are many different understandings of these three terms—deinstitutionalization, community, and least restrictive alternative. In fact, maybe there are almost as many different understandings as there are people in this room. Yet, we've planned mental health and mental retardation services—and sometimes even entire service systems—based on the assumption that there's a shared understanding of these very vital words.

Sometimes we've found that our vagueness has resulted in irrelevant—maybe even inhumane—programming.

SEMANTIC GAMES

Which brings me to my major point:

For reasons that are numerous and diverse—and certainly not entirely clear to me—people who plan services for, and deliver services to, the mentally disabled play a lot of games with abstractions—semantic games.

I think that there are two major varieties of these games—number games and word games. And every once in a while the two are combined into one huge super game.

Let me give you an example of what I'm talking about:

Maybe you're aware that throughout the country there's been a problem of rapidly increasing populations of homeless people: people who have no place to live. It's fairly widely agreed now that a substantial portion of that population (the exact percentage varies among communities) consists of people who are chronically mentally ill (Bachrach 1984c). For several years, now, the federal Department of Health and Human Services has been estimating that there are about 2 million homeless people in the country and that about half of them—some one million—suffer from conditions that come broadly under the heading of alcohol, drug abuse, or mental health problems (Alcohol, Drug Abuse and Mental Health Administration 1983).

Now, what do you do if you're the federal government, and you've been saying that there are two million homeless people out there, and that about half of them are very sick and need some assistance? Well, you can either deal with a problem like this one substantively—by trying to do something to relieve the situation through allocating special funds or designing special programs. Or else, if you cannot or do not want to deal with it substantively, then you can deal with it through abstractions, i.e., by a semantic game. And if you the do latter well enough, maybe you won't have to deal with the substantive part at all!

In this particular case of homeless citizens, the federal government has apparently chosen to deal with the problem of homelessness in a non-substantive way by playing a decisive numbers game. After the estimate of two million homeless people had been floating around for a while, the United States Department of Housing and Urban Development (1984) came out with a much smaller estimate of 250,000 to 300,000 homeless people—thus cutting the original estimate by over 85 percent.

Never mind that a lot of very reliable scholars, organizations, and individuals have condemned the smaller estimate as being not only grossly inaccurate (Goode 1984; Guillermoprieto 1984; Harris 1984; McCarthy 1984a, 1984b; Pear 1984), but, worse, a deliberate attempt to mislead (Hopper 1984; Kamen 1984). Never mind that there has been sufficient outrage that Congressional hearings—with damning evidence against the estimate—have been held. The smaller estimate sticks—because it effectively provides a way to get rid of an embarrassing problem that doesn't lend itself to quick and inexpensive solutions. If you can get away with saying that the problem of homelessness isn't really very significant numerically, then maybe you can rationalize not dealing with it, and no one will fault you.

Now, semantic games vary among themselves in a number of ways. Some are much more subtle than others. At one extreme we have semantic games that are played quite deliberately. They are conscious efforts that have the express purpose of gaining a particular advantage. They make calculated use of catchwords or vastly oversimplified statements in order to gain some political or financial ground.

The journalist Ward Sinclair (1982) describes a deliberate semantic game that involves migrant farmworkers—and we're all familiar with similar ploys in our own field. I give you this example from another field, because sometimes it's easier to understand these things from a distance. Sinclair writes that in some places migrant farmworkers are now being called "sharecroppers." And he describes this as a "linguistic nicety that allows the farmers who employ them to avoid paying minimum wages and to escape Social Security, unemployment, and workmen's compensation benefits."

At the other extreme are semantic games that are so complicated and so subtle that they even fool the people who invent them. We rationalize a lot of what we do—and also a lot of what we *don't* do—by playing these subtle games (Edelman 1977; Fiske 1982; Newman 1975; Talbott 1975). They help us to evade, deny, displace, and obstruct.

I think that one of the most insidious semantic games that we play revolves around the denial that the mentally ill are in fact ill (Talbott 1984). Sometimes we go to considerable lengths to reinforce this notion (Szasz 1982), but that doesn't make the illness go away.

Several years ago the journalist Susan Sontag (1979) wrote about the dangers inherent in this kind of denial with respect to nonpsychiatric illnesses. In her classic book, *Illness as Metaphor,* Sontag focused on tuberculosis and cancer and talked about people's tendency to act as if these conditions would not occur if the patient, or society, had somehow behaved differently—perhaps followed a more healthful or more moral life style.

The purpose of Sontag's small but brilliant volume is expressed in her prefatory statement, which I'd like to quote: "My subject is not physical illness itself but the uses of illness as a figure or metaphor. My point is that illness is *not* a metaphor, and that the most truthful way of regarding illness . . . is one most purified of, most resistant to, metaphoric thinking."

I believe that Sontag's point also applies in the case of chronic mental illnesses. It's often so hard for us to confront the reality of these illnesses that we want to deny their very existence. And, when we do this, we professionals aren't really too very different from the citizen in San Jose, California, who wrote to Ann Landers (1981): "We hear so much about mental illness these days. Why isn't there more emphasis on mental health?"

What's wrong with evasion and denial? Well, the trouble with them is that, despite our good intentions, they hold the potential for ultimately penalizing mentally disabled people and for making their lives more burdensome.

Using the example I just gave you, I'd say that it's easy to jump from denying the existence of illness to denying the need for special services in the case of people who are chronically mentally ill. And, in fact, this is exactly where some of our semantic games have gotten us. We've now apparently granted some public officials permission to insist that mentally ill people who are undomiciled are that way by choice (Williams 1984). Implicit in this is the notion that they are not really entitled to assistance.

Some of the semantic games that we play in mental health and mental retardation are so powerful that—as I hinted earlier—they even deceive those among us who consider ourselves to be sophisticated professionals and who are thoroughly committed to the mentally disabled.

For instance, we talk about "admission diversion" policies (Dionne 1978; Morrissey & McGreevy 1982; Pepper & Ryglewicz 1982; Shapiro 1983; Sullivan 1979a, 1979b), when, what we really mean is, "We don't have the resources or the will to take care of this patient or client in this place. And we hope that somebody else will get us out of being responsible for this patient or client, and take him or her off our hands."

Another example:

We talk about a patient's or client's "continuity of care" (Bachrach 1981; Wasylenki & Goering 1984) when what we really mean is that we've written the name of a referral agency on his or her discharge summary. And we hope that the patient or client will initiate the contact for that referral and carry through—because we're not really set up ourselves to do that.

And another:

We talk about the "exceptional" child, when, what we're really talking about is an individual who needs exceptional kinds and exceptional quantities of care. And we overlook the fact that, when we use this euphemism with the object of combating stigma, we also run the risk of reducing the public's awareness of severe disability—and of the need for special resources. The anthropologist Nancy Scheper-Hughes (1983) very appropriately reminds us that substituting a euphemism for a technical term without addressing contextual concerns can ultimately act to a patient's or client's disadvantage.

And another:

We refer to the "revolving door" pejoratively (Geller 1982), as if it implies that our service initiatives—and, worse yet, our patients and clients—have somehow failed (Harris & Bergman 1984). Paradoxically, we allow that people who have *other* kinds of chronic disabilities may periodically need to be admitted for inpatient care. But with the mentally disabled, we're uniquely insistent that patients and clients always have to move forward along some imaginary continuum of "progress."

And one final example:

We emphasize the importance of "aftercare" services for the mentally disabled in much of our programming. Aftercare services are supposed to facilitate the patient's or client's transition from institutional to community living. And we emphasize this aftercare, even though fewer and fewer mentally disabled individuals are now entering institutions in the first place. And those who do enter institutions today usually stay only a few days or a few weeks (Bachrach 1984b; Goldman et al. 1983)—hardly long enough for them to become products of institutional environments. What we don't seem to realize is that focusing on aftercare really serves a gatekeeping function.

It's a strategy that effectively keeps a number of people out of the service system. Because they've never been inpatients, they just don't qualify for aftercare.

I could go on and on, but I'm sure you get the idea. The semanticist Hayakawa (1972) warns us that "fine-sounding speeches, long words, and the general *air* of saying something important are affective in result, regardless of what is being said." When we hear impressively worded statements, Hayakawa tells us, we may "stop being critical altogether."

This is especially true in the case of words and statements that relate to certain kinds of policy decisions. It's very easy for us to accept words in place of deeds, when the words sound impressive and the deeds are hard to accomplish.

In fact, semantic games seem to permeate all aspects of service delivery for mentally disabled people (Melito 1982; Talbott 1975; Wilder & Karasu 1977). On the conceptual level, we sometimes use terms that are so vague that they limit our ability to think clearly about the things we need to deal with. And, often, we are not even aware of the fact that some of these terms are imprecise or that they have multiple meanings.

In addition, we often use catchwords, buzzwords, euphemisms, slogans, and metaphors to minimize the complexity of the problems we need to resolve.

Let me give you an example of this from current events:

We're all familiar with the federal government's wish to limit social program entitlements to people who are "truly needy." Well, apparently, the people who gave us the notion of the truly needy have tried, in this election year, to tighten up that slogan—and to change it to the "very truly needy." An editorial in the *Washington Post* raises these rhetorical but nonetheless thought-provoking questions about the proposed change. It asks, "What if someone who was only mildly hungry got free food?" And "what if only the somewhat homeless got a place to live?" (Truly Nutty 1984).

Semantic games get in the way of proper program evaluation, too. They give us problems when we try to assess the outcomes of our interventions accurately and dispassionately (Bachrach 1980b, 1982; Bachrach and Lamb 1982). How in the world, for example, can you evaluate a community support program when there's no rigorous and operational definition of what a community support program is or what it's supposed to do (Bachrach 1982)?

I think that my favorite example of how semantic games interfere with evaluation, though, is in the general failure in much of our research to make a distinction between "readmission" and "relapse." We often conduct studies as if a person's hospitalization is evidence that he or she has had an exacerbation—and, conversely, as if a person's lack of hospitalization is evidence that he or she is doing well clinically. But, of course, people can be hospitalized—or *not* be hospitalized—for a lot of reasons that are entirely non-clinical (Franklin et al. 1975; Hausman 1982; Solomon & Doll 1979):—reasons like simply having no place else to go. It's a mistake to evaluate a patient's or client's status—or to assess a system's quality of care—on the basis of hospital utilization statistics.

Sometimes our semantic games lead us to come up with some very good answers—but we lose sight of the questions. For example, we do this when we look at an isolated successful program for mentally disabled people and conclude from its existence that the entire deinstitutionalization movement is "working" (Bachrach 1980b). When we do this, we're engaging in something that semanticists call "metonymy." We're focusing on one aspect of an event, in order to make generalizations about the entire event. According to one semanticist, Edelman (1977), this kind of substitution of a part for the whole is really a subtle device for helping us to accept problematic situations by persuading ourselves that they've been resolved in a rational way.

In this connection I'd like to mention briefly one really troublesome area that's been confounded by semantic games. I want to mention this only parenthetically, because I could easily get carried away and spend my entire time this afternoon talking to you about this particular aspect of semantics. It has to do with the tremendous problem that we have in describing residential facilities for the mentally disabled.

We talk about residences for mentally disabled people as if places that share the same designation are uniform—as if they're all pretty much alike. So we say that a specific patient or client is now ready for a halfway house or that he or she really belongs in a nursing home. We say these kinds of things as if there's a predictable uniformity in the places to which we give these names.

But the truth is that halfway $house_1$ may be nothing like halfway $house_2$; nursing $home_1$ isn't necessarily very much like nursing $home_2$; state $school_1$ is entirely different from state $school_2$; and so forth (Bachrach 1980a). And, in fact, there's probably as much variation *within* classes of residential facilities as there is *among* them—if not more.

Now, originally, the concept of the least restrictive alternative was supposed to serve as an aid in planning appropriate and relevant services for mentally disabled people. But I would suggest to you that the concept of the least restrictive alternative is really too imprecise and too unrefined to serve us in that way. In order for a concept to be useful as a planning aid, it needs to be precisely defined, and its empirical referents need to be very clearly designated. But these requirements are certainly not met with the concept of the least restrictive alternative. To the contrary, the term is generally used so loosely that it reminds me of what Humpty-Dumpty said in *Through the Looking Glass* (Carroll 1969). He said, "When I use a word it means just what I choose it to mean—neither more nor less."

When we try to analyze the concept of the least restrictive alternative, we confront the fact that "to restrict" can mean more than one thing. It can either mean to *limit*, to *confine*, or *to restrain*. These three meanings, although they're somewhat related, actually deal respectively with different aspects of patient or client care. They deal with the *personal autonomy*, the *social isolation*, and the *civil rights* of mentally disabled people—so that when we seek to limit the restrictiveness of somebody's environment, we may be referring either to the person's personal autonomy, to his or her social isolation, or to his or her civil rights, or maybe to some vague combination of all these qualities.

What we usually do, in effect, then, when we use the concept of the least restrictive alternative is ignore the fact that restrictiveness is multifaceted. We act instead as if it has a unitary meaning. We oversimplify it, so that it has only one referent—a geographical referent that's based on where a person lives.

But let me put some questions to you. Is it nonrestrictive to let a patient or client live on the streets where he or she can be robbed, beaten, or raped? Where he or she doesn't even get the rudiments of subsistence? Where he or she can die of exposure or starvation? Is it nonrestrictive to place a patient or a client in a noninstitutional setting, even when he or she has expressed a contrary wish: to be inside an institution? Or when he or she lacks the competence to make that kind of a judgment?

What I'm suggesting to you, of course, is that it's perfectly possible for us to reduce restrictiveness in the sense of social isolation—to remove a patient or a client from an institutional setting—at the same time that we *increase* his or her restrictiveness in the sense of personal autonomy or civil rights. We may put a person into the community—but at the same time expose him or her to an increased risk of psychological stress or personal danger.

Obviously, the notion of the least restrictive alternative, as we generally use it, is missing something important. And that important something is the consideration of individual need.

I'm going to be coming back to the notion of the least restrictive alternative in just a little while. But the point I want to make right now is that it's the total lack of understanding of the ways in which we use words—and of the power that's implicit in those words—that make the semantics of services for the mentally disabled so very fascinating—and potentially so very insidious. Even when our intentions are honorable and humane, language can sometimes play powerful tricks on us. Even when our intent is to provide more humane care for the mentally disabled, that intent can be subverted by our lack of specificity.

YOUNG ADULT CHRONIC PATIENTS

Of course, not all semantic games are necessarily destructive. From time to time, we engage in a semantic game that actually enhances our ability to serve the mentally disabled. In the field of mental health, for example, we're currently playing a very involved semantic game called "young adult chronic patients." I call this an involved game—a very complicated game—because it has both some positive and negative aspects.

What we've done is isolate a group of patients and made the judgment that the service system holds insuperable barriers for them. And we've identified this group of patients largely on the basis of their age—18 to 35 years (Pepper & Ryglewicz 1984). By focusing our attention on these young patients, we've been able to sort out some very serious deficits in our service system. This, in turn, enables us to think about revamping our services in an entirely new way (Bachrach 1984b).

But on closer examination we find that it's not their age as such that differentiates these young adults from other chronically mentally ill people.

The thing that makes them different is their collective and unprecedented impact on an unyielding service system (Bachrach 1984b). So, although the youth of these patients has become a focal point of our concern, that's not the basis for their service deficits. What *is* important is the fact that they, as the first generation of patients to seek care in an essentially deinstitutionalized service system, are misfits within that system. The available interventions are not congruent with their special needs. Once again, I would point to aftercare services as an example of programming that's more appropriate for a former generation of chronic mental patients.

As a concept, the young adult chronic patient has both positive and negative aspects. On the positive side, the concept serves as an ideal construct for us—a construct that enables us to appreciate some of the deficits of the mental health service system better than we did before the concept was introduced.

But what's the negative part? Well, the fact is that the concept of the young adult chronic patient is being used loosely and is becoming cast in concrete in a very unrealistic way (Bachrach 1984b). To be more specific, the baby boom generation, which was born between 1946 and 1961, provides the denominator for the young adult chronic patient population as it was originally described in the literature a few years ago (Pepper et al. 1981). But this population has now begun to age, and it's currently between the ages of 23 and 38. What's more, a simple look at the nation's demography shows us that we'll soon have a bulge of middle-aged chronic mental patients—and then, not too much later, a bulge of geriatric chronic patients.

Are we going to be ready for them? Or are we still going to be perseverating with the need to serve young adults from 18 to 35 as the most problematic target population? I get the distinct impression from at least some of the people who use the concept of the young adult chronic patient that they're so tuned in to its positive value, that they're simply not seeing the other side—the risks that are attached to this concept.

DEINSTITUTIONALIZATION

I wanted to mention the concept of the young adult chronic patient at this time, because it makes a very appropriate lead-in to another subject: deinstitutionalization. When we think about young adult chronic mental patients in today's system of care, we're inevitably concerning ourselves with the policy of deinstitutionalization—with its practices and its implications.

In fact, as I think about services for the mentally disabled as they've developed in recent years, it's really hard for me to consider them in any context other than that of deinstitutionalization. Deinstitutionalization is, I think without any doubt, the single major policy thrust that's determined the direction of mental health and mental retardation services for the past two or three decades. In fact, it's predominated to such an extent that it's very difficult for most of us to imagine serving the mentally disabled in anything other than service systems that are essentially deinstitutionalized in concept and direction—if not entirely deinstitutionalized in fact.

Deinstitutionalization is also, I think, the most popular semantic game in mental health and mental retardation today. Everybody who plays it is in there to win. Listen to how some different people and documents describe and define deinstitutionalization:

- An editorial in the *New York Times* defines deinstitutionalization simply as "moving mental patients from enormous, remote hospitals into small community residences" (Willowbrook Plan 1982)—a very simple statement of a changed locus of care.
- Richard Scheerenberger (1977), the Director of a state facility for the mentally retarded in Wisconsin, calls deinstitutionalization "one of the most significant concepts affecting contemporary programs for mentally retarded persons." And he notes that its outcomes have been both positive and negative.
- The sociologist and public policy analyst Amitai Etzioni (1976) refers to deinstitutionalization as a "policy fashion" that, by condemning traditional care for the mentally disabled, "romanticizes the benefits of community-based care."

■ The current President of the American Psychiatric Association, John Talbott (1979), says that deinstitutionalization is a misnomer that should be replaced by the term "transinstitutionalization" to indicate that "the chronically mentally ill patient [has] had his locus of living and care transferred from a single lousy institution to multiple wretched ones."

■ The psychiatrist Mathew Dumont (1982) writes even more pointedly. He says: "Let us stop the cant and quibbling. This thing, 'deinstitutionalization,' is nothing more or less than a polite term for the cutting of mental health budgets."

■ Edward Koch, the Mayor of the city of New York, tells us that deinstitutionalization is a "fancy word" that describes "dereliction of duty" on the part of the state of New York toward its mentally disabled citizens (Sullivan 1983a). Meanwhile, the state of New York argues back with a different understanding of the term and asserts that the policy of deinstitutionalization—in the sense of releasing patients from state hospitals—has now been discontinued (Sullivan 1983b).

■ Shari Thurer (1983), a rehabilitation counselor in Boston, points out that deinstitutionalization is a women's issue, because, ultimately, the burden of community-based care falls upon family members, and most particularly upon the women in those families—a view that is, incidentally, borne out by research findings (Froland 1982; Hatfield 1978; Hatfield et al. 1982; Holden & Lewine 1982; Spaniol & Jung 1983).

■ Most often, the word deinstitutionalization refers to people—that is, we speak of deinstitutionalized patients or clients. But sometimes the word is also used to refer to service systems, or even to specific services—so that a newspaper article describes a nursing home as being "painstakingly deinstitutionalized to provide a gracious personal atmosphere for its aged guests" (Goldsmith 1981).

Maybe some of our problems with the term deinstitutionalization can be traced back to the fact that the word "institution" itself has a variety of meanings (Jones & Fowles 1984). But, for whatever reason, deinstitutionalization has proceeded in the absence of a consensual understanding of its meanings, its referents, and its purposes.

So—what do we *really* mean by that very busy word, deinstitutionalization? I've never found out its precise origins, even though I've been preoccupied with its consequences for a good many years now, and I can tell you that I've been criticized more than once for the fact that I've made

deinstitutionalization my major research focus and area of study. The fact is that a lot of people simply object to my using this word. They see it as imprecise, or inaccurate, or confusing—and, of course, they're perfectly right.

I was interested to read recently that there's a sound-alike in the field of economics: "deindustrialization." It's a term that's apparently used to refer to the effects of foreign trade policy on American industry. This is what the renowned economist, Robert Samuelson (1984), has to say about deindustrialization: that it's "one of those mongrel words that has crept into the language and ought to be kicked out. The purpose of language is to inform; this word misinforms," says Samuelson.

Sound familiar?

But you have to recognize that even people's reservations about the word deinstitutionalization haven't stopped them from using it—and using it widely—either as a rallying cry or as a planning concept. What's really strange about this is that when people *do* use the word, they're likely to act as if everyone else uses it just as they do! And they seem to be blissfully unaware of the confusion that multiple definitions have wrought.

Nevertheless, there is a core of agreement. I think that many people would be ready to agree that deinstitutionalization refers, generally, to our recent efforts to reverse the trend of providing treatment or care for mentally disabled people in custodial and physically isolated environments. It's closely related to notions like "normalization" (Wolfensberger 1970) and "mainstreaming" (Silverman 1979)—whatever those are. But this is only a superficial kind of a definition. It doesn't really tell us a whole lot about the dynamics of deinstitutionalization.

In fact, one of the first things that happens when you become a serious student of deinstitutionalization is that you notice that people usually just don't bother to define the word. They certainly don't often bother to state its limits. I don't think that that's altogether accidental. As a vague and poorly defined term, deinstitutionalization allows us to ignore some of the things that we couldn't get away with avoiding, if we were a little bit more precise.

Again, I think that we do a lot of this unconsciously. But I do think that the term deinstitutionalization serves to provide legitimation for some very complex—and sometimes controversial—planning decisions.

So, if we don't define the word deinstitutionalization too carefully—if we don't bother to state its limits—then maybe we can avoid dealing with some of its implications.

Fact, Process, and Philosophy

For a number of years now I've used a two-part definition of deinstitutionalization in my work. I've defined it as the shunning, or avoidance, of traditional institutional settings, particularly state hospitals and state schools, for the care of mentally disabled people and the concurrent development and expansion of community-based facilities for the care of this population (Bachrach 1976). In 1978 I expanded that definition by analyzing the term conceptually. In an article in *Hospital and Community Psychiatry* that year, I suggested that there are at least three distinct—though closely related—aspects of deinstitutionalization. Deinstitutionalization is a *fact*. It's also a *process*. And it's also a *philosophy*.

Now, what exactly did I mean when I wrote that? I meant, basically, that deinstitutionalization is a very complicated term that we need to treat with respect—and that by oversimplifying the concept, we've brought grief to our patients and clients and brought confusion to ourselves. I cautioned then that oversimplification would only cause us to lose sight of what deinstitutionalization is really all about.

As a *fact*, deinstitutionalization can be thought of as an objective series of events—events that are manifested in a massive shift in the locus of care for the mentally disabled. If you take a look at utilization statistics in this country, you'll see that inpatient care—and, more specifically, institutional inpatient care—for the mentally disabled has vastly decreased as a proportion of all care—at the same time that outpatient care has increased in a most dramatic way (Goldman et al. 1983; Hill & Lakin 1984; Thompson et al. 1982). It's this shift in patient and client care settings that gives substance to deinstitutionalization as a fact.

And deinstitutionalization as a fact is exactly where many understandings of the term begin—and end. But, in addition to its being a fact, deinstitutionalization is also very much a *process*. Specifically, deinstitutionalization is a process of social change—of movement away from one orientation in patient and client care to another orientation that's radically different. This process, which has been going on for two or three decades in most parts of the country, has all by itself affected the lives of the mentally disabled.

In other words—and I can't stress this too strongly—the very process of change has created its own momentum. Deinstitutionalization, as a process, involves all the elements of the service system. It's a dynamic and ongoing series of accommodations and shifting boundaries. And, not surprisingly, it's caused severe disequilibrium in the service system—disequilibrium that's currently reflected in a number of serious problems. These problems have been my major preoccupation for quite a few years.

So, deinstitutionalization isn't only a fact; it's also a process—a process that has had some consequences of its own. And if we look at it simply as numbers of people moving from one place to another, we can easily lose sight of the process.

But deinstitutionalization is something else as well. It's a *philosophy*—a philosophy that has its roots in post-World War II America, when a variety of civil rights protests were gaining widespread support. Like other civil rights protests in that post-war era, deinstitutionalization emphasized the inalienable rights of disfranchised individuals—in this case, the mentally disabled—and their legitimate claims on society. The deinstitutionalization movement undertook no less impressive a task than one of "humanizing" care for the mentally disabled—of reversing the dehumanizing influences that were widely thought to be the inevitable accompaniments of institutional residence.

Now, to say that deinstitutionalization was ideologically part of the civil rights movement is not the same thing as saying that it lacked commitment from other ideological constituencies. As a matter of fact, deinstitutionalization also held great appeal for fiscal reformers in addition to social reformers. In addition to the belief that community-based care is more humane than institutional care, there was a second belief: that community-based care is also less expensive (Cramer 1978; von Hoffman 1980). Usually, social reformers and fiscal reformers don't have a whole lot to say to one another, but in this case they did. And this coalition—this rare marriage of two ordinarily antagonistic constituencies—gave the deinstitutionalization movement unprecedented impetus.

So that's what it was all about. Community-based care was supposed to be both better and cheaper than institutional care. And the fact that these assumptions were never really tested—that they were really matters of faith,

not science—didn't make a bit of difference. It's a fairly common observation in the field of semantics that assumptions don't need to be tested in order to be used as justifications. They only need to be believed (Edelman 1977; Hayakawa 1972). In fact, maybe it's better if they're *not* tested!

There were a few other assumptions that became part and parcel of the ideology of deinstitutionalization, too. For example, it was widely assumed that members of the community and community organizations would rally—and that they would take the initiative in caring for the mentally disabled. And it was also assumed that, somehow, with a changed locus of care, the stigma that's associated with mental disability would disappear. These assumptions weren't tested either, but they certainly were believed.

But I think that from the point of view of service planning, the most important of the untested assumptions in deinstitutionalization was the thought that communities could and would provide alternatives for the full range of services and functions that are associated with institutional care (Bachrach 1976, 1983a; Shepherd 1982). It was assumed that the community could and would provide long-term treatment and residence for the most disabled among our mentally ill and mentally retarded citizens. And it was assumed that the community could and would assert itself to assure that patients and clients would be adequately monitored over long periods of time.

Still more: It was assumed that the community could and would render relief to the patient's or client's family and that it would create and reinforce social networks for the disabled person. And that it would serve as an advocate for the patient or client, when he or she was having trouble in gaining access to goods or services.

You'll recognize, of course, that all of these functions are part of the institutional sociology: part of the concept of total care that goes with institutionalization. And we just assumed very early in deinstitutionalization—either explicitly or implicitly—that these functions could readily and easily be picked up by the community.

What a number we did on ourselves!

What I'm saying to you, then, is that if you have an ideology that's strong enough to motivate you to action, and you use words and concepts that are vague enough so that the ideology isn't put to a proper test—then you have

the makings of rapid, precipitate, and sometimes manifestly harmful social change. And that's what deinstitutionalization, in most of the country, was *really* all about!

To this day, many of these assumptions continue to be accepted on faith, even when we have evidence that they lack validity both in scientific and human terms. Community tenure—that is, the patient's or client's length of stay in the community—is pretty much accepted today as an indicator of good and appropriate care (Adler et al. 1984). In fact, it's accepted to such an extent, that it's the most widely used outcome measure in our field (Bachrach 1982).

But, if you think about it, simple measures of community tenure don't tell us anything about how a patient or client is doing or feeling and whether the quality of his or her life has improved or deteriorated. The Canadian psychiatrist Vivian Rakoff (1976) is fully justified in warning us that we must not let our statistics persuade us that "we have performed a social miracle and there are no more mad men [or women, I would interpolate] in the world."

COMMUNITY AND ASYLUM

Up to this point, I've been trying to accomplish essentially two major things. First, I've been trying to build up a logical structure for understanding some current problems that we have in serving mentally disabled people. And second, I've been trying to demonstrate how conceptualizations and semantic constructs that have been part of the deinstitutionalization movement from the very beginning have placed us in jeopardy. And we owe much of this to the fact that deinstitutionalization is a series of events that encompass fact, philosophy, and a process of social change. What's more, there's a serious disjunction between the fact, the process, and the philosophy of deinstitutionalization.

And that's not all. The concept of deinstitutionalization has had good company. It's been supported in its inadequacy as a planning concept by a host of other similarly vague notions.

Let's look at the word "community" very briefly. Deinstitutionalization is a neologism—a fabricated word that you don't find in the dictionary. But a word doesn't need to be a neologism in order for it to be inadequate for planning purposes. Even a good old word like community can be similarly limited. Community has many, many definitions—and, by some of them, a state hospital or a state school would itself qualify as a community!

I can't resist digressing and saying just a word or two more about community. We play a very good semantic game with community. We use it in conjunction with many other buzzwords—like "catchmenting," "support system," and "involvement"—to justify our program initiatives.

Now, a number of authors have written some very learned analytical articles that deal with what community means—with its multiple definitions and its subtle implications (Back 1970; Huffine & Craig 1973; Kantar 1981; Larson 1977; Luloff & Greenwood 1980; Panzetta 1971; Regester 1974). But we in mental health and mental retardation do all those worthy scholars one better: we already KNOW what community is. It's any place that isn't an institution!

Is it any wonder that we've had problems with "community" in service planning and service delivery?

One particular semantic transmutation that's done a lot to confound issues in the care of the mentally disabled is our confusion with the concept of "asylum." If we've glorified the concept of the least restrictive alternative, then we've done just the opposite with the concept of asylum. We've made a villain of the term—at least when we apply it to the mentally disabled. (You'll notice, of course, that we use a different standard when we apply asylum to political refugees. And we're also very involved at this time in many parts of the country with the hospice movement (Teltsch 1980)—which can really be construed as a form of asylum. But, somehow, we think of asylum for the mentally disabled in a different way.)

I think our reaction to the word asylum can be largely attributed to the fact that the word means more than one thing. The dictionary defines asylum as "an inviolable refuge; a sanctuary; a place where one is safe and secure." But the dictionary also gives as a second definition of asylum "the protection given by a sanctuary or a refuge."

So the word asylum really has two meanings—first, as a place; and, second, as an event. Asylum—that is, safe haven, is something that *may* be provided in an asylum—that is, a place where protection is offered. I think that this dual meaning of the word asylum has really gotten us into a lot of trouble.

Let's take a closer look at this situation:

It's fairly widely held in planning circles today that asylums are intrinsically undesirable places that breed their own pathology (Goffman 1961) and that they should be supplanted by community-based service sites. Of course, this notion has a lot of historical support. I don't think that any of us would want to have to defend the abuses that took place in institutions that we called asylums in past years. And I think that most of us today are very wary lest those same abuses somehow be reintroduced, even though there's some pretty strong evidence now that long-term care facilities actually provide the settings of choice for *some*—not all, but some—mentally disabled people (Group for the Advancement of Psychiatry 1982; Peele 1983; Peele et al. 1977).

In any case, though, when we've tried to do something about the pathological aspects of places called asylums, we've become confused by our own rhetoric. We've overlooked the very basic consideration that institutional care involves more than just a residential setting. As I pointed out earlier, institutional care also covers a suprisingly complex set of functions in the service of the mentally disabled. And one of those functions—a critical one—is providing access to safety and security for those patients and clients who have such a need.

Obviously, this has been a classic kind of baby-and-bath-water situation. And, needless to say, it's sometimes had devastating consequences for patients and clients. To put it simply, there's often no place in today's service system where people who need asylum can go—where they'll be psychologically, not to mention physically, safe and secure (Bachrach 1984a; Sheehan 1982).

Now, I feel that it's important for me to issue a disclaimer at this point. Very often, when I say the kinds of things I've just been saying, people seem to hear me say something else. They seem somehow to be the victims of their own semantic games. So they sometimes hear me proposing a return to the era of institutional care. Not only am I not saying that; I don't even think it's feasible. Institutions themselves are serving more and more as acute care facilities, and the old time institutions seem to be slipping away (Goldman et al. 1983).

So, please don't construe what I'm saying to you as either an acceptance of the quality of care that used to prevail in places we called asylums or as a call for us to return to the "good old days." I'm most emphatically not supporting either thing. All I'm suggesting to you is that the concept of total care for some mentally disabled people (Freeman 1983)—a kind of total care that includes asylum care—is a valid and appropriate concept. Not for all patients and clients, but for some. And that, in getting rid of places called asylums, we've too often forgotten that this kind of care is critically needed by some of the people we're trying to serve.

Some people have a temporary or episodic need for asylum. And other people seem to have a continuous and never-abating need. But for a portion of the population of mentally disabled individuals, we can't ignore the need for asylum—at least if we mean to provide for these people in a relevant and humane way.

And I'm saying one more thing, too. I'm saying that, to me, at least, the "where" of asylum is a lot less important than the "what." We now know that it's potentially possible to provide asylum in either institutional or non-institutional settings (Lamb 1979). If we don't want to do it in one place, then we simply have to do it in another. But we can't abandon it altogether.

And we simply must not repeat the terrible error we've made over and over again in deinstitutionalization—the error of removing institutional care before we've provided viable alternatives in the community, the error of eliminating asylum *care* as we've eliminated *places* called asylums.

Deinstitutionalization, if it's going to be done right, isn't all glamor. It isn't all patients improving, chronicity going away, and communities reaching out to assist the mentally disabled. It's sometimes those things, of course. But

sometimes it's less appealing things, too—like providing care in the community to people that we used to lock away because we didn't want to see them and even going to bat for them when other people don't want to have them around. It's seeing to it that these people are fed and clothed and given medical care, even when their paranoia about us causes them to avoid us and wander homeless on the streets. Most basically, it's providing them with shelter and a place where they can be physically safe while we try to figure out ways to treat their illnesses, mitigate their disabilities, and quiet their special demons.

This brings us full circle to the notion of the least restrictive alternative.

If you think about it, that concept provides what's basically an environmental, not an individual, response to questions about service planning for the mentally disabled. It emphasizes the qualities and characteristics of *places* —state hospitals or state schools, or nursing homes, or halfway houses, or board and care homes—instead of the qualities and characteristics of *patients* or *clients*. It says, in effect, that a particular place is intrinsically superior to some other place for people who are mentally disabled.

When placements are made according to this kind of judgment, it becomes all too easy to lose sight of the fact that some patients or clients need asylum quite independently of where it's provided and that that need supersedes geography. Similarly, other patients or clients need other kinds of services—medical, psychiatric, social, or rehabilitative services—again, quite independently of the geography of the situation.

This is why Joel Klein (1981), an attorney for the American Psychiatric Association, claims that the concept of the least restrictive alternative is "fundamentally flawed." He summarizes some of its basic logical limitations with these very eloquent words: "Treatment and liberty cannot be viewed as independent variables, thereby suggesting that one—treatment—can be kept constant, while the other—liberty—is titrated along a continuum of restrictiveness. The provision of treatment is ultimately a clinical matter."

IMPLICATIONS AND CONCLUSIONS

Where does all of this leave us?

I've been speaking about some extensive problems that are associated with serving mentally disabled people—problems that are closely associated with the ways in which we use language: the semantic games that we play. Are there any solutions to these problems? Can we possibly reverse our propensity for imprecision and fuzzy thinking? Or are we doomed to having a service system that's built on triteness at best and on dangerously vague concepts at worst?

Well, I suppose I'm a Pollyanna—and I guess that in this business you have to be. And so I would say to you that we *can* do something about these problems. But only under certain circumstances. And certainly not overnight. And in no case is the process likely to be an easy one.

I would suggest to you that we need to take a couple of steps in order to begin to turn things around.

First, I think we need to renew our sense of commitment to the mentally disabled in these very hard times. I think it's easy for us to get demoralized and discouraged by the enormity of our problems and by the confusion we've had in the past. It's particularly easy to do this when there seems to be such gross insensitivity on the part of people and agencies who have the power to help.

But we can't let our past errors discourage us. Instead, we need to go all out to let those errors teach us. We certainly have a lot to learn. But we also have a lot to learn from.

Second, I think we need to work hard to educate ourselves to understand the power of words, as Giamatti described it—so that we can control them instead of letting them control us. We need to know *why* we play semantic games and what purposes they serve.

I'd like to expand on this second point just a little bit before I bring this talk to a conclusion.

I think we all know that every time we plan services based on fuzzy thinking and imprecise concepts, we increase our already considerable

potential for confusing, confounding, and obstructing care for the mentally disabled. So why do we continue on this path? Why don't we just pull ourselves together and clean up our semantic act?

Well, I think that the answer to this question takes us back to the nature of semantic games—to their subtlety and their basic purpose. I believe, very simply, that it's in the nature of these games to allow us to deceive ourselves.

The point is often made that language has social uses that extend beyond denotation and description (Edelman 1977; Hayakawa 1972). Words reflect our ideology, our beliefs, and our social status. And, as I indicated at the beginning of this talk, words have the power to determine the questions that we ask—and, coincidentally, the questions that we never ask.

Even imprecision in language can serve important functions, though they're not necessarily conscious. For example, imprecision lets us read into any word or concept whatever definition fits our own experiences or purposes. In this way, imprecision can eliminate our need to ask whether there are alternative perspectives or points of view.

In addition to enabling us to maintain our beliefs, imprecision can also serve the further purpose of covering up inaction. When things *sound* busy, it becomes easy for us to persuade ourselves that they *are* busy. Slogans and other bandwagon words, irrespective of how well they reflect reality, are capable of deflecting critical thought.

So, if we can rant about deinstitutionalizing people to less restrictive alternatives and even go to court to support the morality and legality of such measures, then maybe we won't have to confront the *really* hard things—like implementing appropriate standards of care in our treatment facilities or engaging reluctant service providers in our efforts. We leave those matters to take care of themselves, while we look the other way.

In addition to helping us maintain our beliefs and assisting us in covering up inaction, imprecision can also serve to preserve the status quo. It's difficult for society—even that part of society that we think of as the mental health and mental retardation system—to accept changes that occur too rapidly. Imprecision helps us to keep the rate of change within the limits of cultural tolerance. It slows us down.

Now, it's not surprising that, when you're starting something new—especially something so revolutionary that it turns around the entire

entrenched system of care for the mentally disabled—that you're going to be more than just a little bit tentative. At some level, you're aware that there are competing goals to which you need to assign priorities and competing populations that you need to serve. At some level, you know that there's a potential for unintended, but nonetheless serious, consequences issuing from your new interventions. And you know that some of your ideas will probably be costly—both in dollar terms and in terms of public approval.

I see our semantic games as an acknowledgment of these kinds of things and even, in some ways, as an effort to ease the transition from an old to a new system of care: a necessary step, if you will. The problem isn't that we've played these games: some of them have been inevitable. The problem is that we won't give them up—that we're so enamored of them, that we hang on to them for dear life.

To say all of this just a little bit differently, I think that, for a variety of reasons, we've *needed* to deceive ourselves in the past. The sociologist in me inclines me to believe that culture traits don't just occur by chance; they generally serve some purpose. And this is true for words, as well as for other items of culture. It's true for our vague concepts and our faulty logic.

But things are different now. The need to deceive ourselves is over, and we have a very different kind of need now—a need for precision, for clearly stated goals, and for carefully worded objectives—so that we can plan our services for the mentally disabled rationally and evaluate their effects realistically and accurately. It's really incumbent upon us now to move ahead—to take control of our language, our concepts, and our logic.

I believe that we've come a long way in improving care for the mentally disabled over the past couple of decades. Today we can identify some of the sources of our problems in providing effective MHMR care. We can take a look at where our vagueness and imprecision have led us. That puts us potentially a giant step ahead of where we were 30 years ago, when we didn't even anticipate that there were going to be these kinds of problems.

Now we need to sharpen up our thinking apparatus. We need to revise our concepts and revamp our logic, so that we can start to take appropriate action in response to the problems that we're now beginning to understand.

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